

# Ending Tuberculosis in England

Accelerating progress of the  
national TB response

## Final report

Inquiry into the Public Health England and NHS England  
Collaborative TB Strategy for England 2015-2020

All-Party Parliamentary Group on Global Tuberculosis

March 2019



THE ALL-PARTY PARLIAMENTARY GROUP

Tuberculosis

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**Registered Contact**

The Rt Hon Nick Herbert CBE MP, House of Commons, London, SW1A 0AA

**Public Enquiry Point**

RESULTS UK, 31-33 Bondway, London, SW8 1SJ

[info@appg-tb.org.uk](mailto:info@appg-tb.org.uk)

## Foreword

Tuberculosis (TB) continues to kill more people each year than any other infectious disease. On 26 September 2018, Heads of State and Government from around the world convened in New York for the first United Nations High-Level Meeting on Tuberculosis (TB). The meeting marked a turning point in the global response to TB with the final political declaration committing to diagnosing and treating a cumulative 40 million people by 2022, including 1.5 million people with drug-resistant TB, the first internationally-agreed treatment target for a drug-resistant infection.

England has seen some of the highest rates of TB in northern and western Europe with a national epidemic that was out of sync with downward trends across the region for a number of years. Rates peaked in 2011, when there were 8,280 cases of TB in England alone at an incidence rate of 15.6 per 100,000 people.

In this context, the APPG actively campaigned for a national Strategy, launching an inquiry and highlighting the urgent need to develop a coherent approach to tackling TB in England, to increase capacity and standardise service provision across local authorities. In 2015, we were delighted to host Jane Ellison MP, then Public Health Minister, for the official launch of the Collaborative TB Strategy for England in Parliament. We welcomed the comprehensive and collaborative nature of Strategy as well as the consistent downward trend in TB rates seen in the years since.

We reached the halfway mark of the Strategy's implementation at the same time as the Heads of State and Government met in New York for the UN High-Level meeting. In order to deliver its own 'fair share' of the 40 million target agreed in New York, the UK will need to treat 21,700 people with TB before the end of 2022. In the context of accelerated action to end TB at the global scale, therefore, this report considers expert evidence received over the last year to evaluate progress made since 2015 and identifies additional steps needed to accelerate progress towards these goals and to secure the long-term sustainability of the national TB response.

We want to offer our sincere thanks to all those who contributed to this inquiry, including the National TB Programme Office, PHE and NHSE, and all the expert witnesses who submitted written and oral evidence. We hope that the findings presented in this report provide a sense of direction for our joint efforts to end TB in England.



**The Rt Hon Nick Herbert CBE MP**  
Co-Chair of the APPG  
MP for Arundel & South Downs



**Virendra Sharma MP**  
Co-Chair of the APPG  
MP for Ealing, Southall

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## Executive Summary

The Collaborative TB Strategy for England has had a positive effect on both TB care and TB rates in England. While it is likely too early to measure the full epidemiological impact of the Strategy itself, preliminary analysis validates the Strategy's approach while also pointing to key opportunities for 'bending the arc' of the national TB epidemic further.

The Strategy has contributed to major innovations in TB control, with cohort review mechanisms, innovative commissioning structures, the routine use of whole-genome sequencing, and technologies such as video-observed therapy, which promise not only to drive case-finding and treatment success in England but also have potential for global application.

Similarly, multi-disciplinary and multi-sectoral governance structures instituted at the national and regional level should be praised, since these offer an important model for the kind of collaborative approach called for at the High-Level Meeting. Room for improvement remains, however, particularly at the regional level where witnesses noted that limited engagement of key strategy partners had hampered progress on key priorities.

There are particular areas of concern relating to the continued diagnostic delay, the latent TB programme's testing and treatment uptake, and work with under-served populations. As a result, evidence of the Strategy's full implementation and impact beyond the 10% annual decline seen from 2011 onwards has yet to emerge.

The inquiry is divided into four key sections. The first chapter provides background to the inquiry, the second an evaluation of the Strategy's overall effectiveness, the third an in-depth analysis of progress on each of the Strategy's 10 evidence-based areas for action, and a final chapter considers the long-term sustainability of the TB response in England. On the basis of the evidence gathered during the course of this inquiry, the report makes a number of recommendations both in relation to each of the ten evidence-based areas for action and the long-term sustainability of the Strategy.

We encourage all Strategy partners to consider each recommendation in turn and to take steps to deliver on the ambition of the Strategy and the targets of the UN High-Level Meeting political declaration.

## Inquiry Recommendations

### *Improve access to services and ensure early diagnosis*

- i. Strengthen awareness-raising activities among healthcare workers, including in areas of low TB incidence.
- ii. Convene stakeholders at the appropriate level to develop fully-funded plans for reducing diagnostic delay, including through improved accessibility of care services, outreach activities and awareness raising, as well as through appropriate commissioning arrangements and the involvement of third sector organisations.

### *Provide universal access to high-quality diagnostics*

- i. Ensure appropriate commissioning of recommended diagnostic tests for TB and LTBI.
- ii. Consider the inclusion of PCR and IGRAs within key performance indicators of service specifications to ensure appropriate commissioning.
- iii. Conduct a comprehensive evaluation of WGS technology to facilitate further learning.

### *Improve treatment and care services*

- i. Establish a National Working Group on TB in low-incidence areas to determine how services can be run and funded most effectively in these areas.
- ii. Explore additional measures to drive local action and leadership, including through more coherent engagement of regional NHSE offices and strengthened accountability measures for Strategy partners.

### *Ensure comprehensive contact tracing*

- i. Improve monitoring and reporting of contact-tracing data at local, regional and national level.
- ii. Evaluate current workloads and ensure appropriate staffing levels for comprehensive contact tracing.
- iii. Undertake necessary capacity building to ensure WGS data is effectively used in contact tracing efforts.

### *Improve BCG vaccination uptake*

- i. Secure BCG vaccination supply from 2019 onwards.
- ii. Utilise COVER data to guide interventions to improve BCG uptake and catch-up programme.
- iii. Facilitate engagement with Royal College of Midwives and other bodies to ensure appropriate training and awareness among healthcare providers.

### *Reduce drug-resistant TB*

- i. Secure sustainable funding for BTS MDR-TB clinical advice service.
- ii. Explore potential role of VOT in TB and DR-TB treatment provision, including appropriate commissioning models.
- iii. Continue to monitor MDR-TB treatment outcomes closely.

### *Tackle TB in under-served populations*

- i. Ensure multidisciplinary care teams are strengthened through active involvement from local authorities.
- ii. Strengthen awareness-raising and active case-finding activities among under-served and hard-to-reach populations, including, where appropriate, through the specialised commissioning of third-sector organisations.
- iii. Fully-fund the roll-out of a national Find & Treat service.

*Systematically implement new entrant latent TB (LTBI) screening*

- i. Accelerate efforts to improve testing and treatment uptake significantly within the LTBI Screening Programme.
- ii. Ensure quality reporting from CCGs who receive funding for the LTBI screening programme.
- iii. Evaluate the cost-efficiency of the LTBI screening programme and, if necessary, consider steps to improve it.

*Strengthen surveillance and monitoring*

- i. Strengthen data reporting on BCG, contact tracing and LTBI programmes in particular.
- ii. Ensure data is actively being used to hold Strategy partners to account for delivering on their institutional responsibilities.

*Ensure an appropriate workforce to deliver TB control*

- i. Make findings from workforce reviews publicly available.
- ii. Improve data reporting to ensure current workforce levels are appropriate and shape investment cases in areas where staffing levels remain insufficient.

*Long-term sustainability of the Strategy*

- i. Begin work to develop a post-2020 TB Strategy for England.
- ii. Work with partners to ensure said Strategy is fully funded.
- iii. Continue the close monitoring of TB rates in England and adjust intervention models accordingly.
- iv. Maintain TB as a strategic priority for Strategy partners.

# Background

## The Strategy

TB rates in England peaked in 2011, with an incidence of 15.6 cases per 100,000 people. Public Health England (PHE) and NHS England (NHSE) launched the Collaborative TB Strategy for England to “build on the assets that the NHS and Public Health England already have in place”. The Strategy recognised the need for multidisciplinary collaboration between public health, clinical services and social interventions, with the aim of achieving “a year-on-year decrease in incidence, a reduction in health inequalities and, ultimately, the elimination of TB as a public health problem in England”.

Following extensive consultation, the Strategy defined ten evidence-based areas for action.

1. Improve access to services and ensure early diagnosis
2. Provide universal access to high-quality diagnostics
3. Improve treatment and care services
4. Ensure comprehensive contact tracing
5. Improve BCG vaccination uptake
6. Reduce drug-resistant TB
7. Tackle TB in under-served populations
8. Systematically implement new entrant latent TB (LTBI) screening
9. Strengthen surveillance and monitoring
10. Ensure an appropriate workforce to deliver TB control

To achieve success in these ten areas, the Strategy also sought to re-organise and resource TB services in England. The following structural and programmatic reforms were announced:

1. Strengthen coordination and oversight of all aspects of TB control by establishing formal TB control boards.
2. Develop clear, evidence-based model service specifications of clinical and public health actions required to control TB.
3. Assess local services against the service specification and develop plans to secure improvements.
4. Establish arrangements to cover the cost of additional services to address specific gaps in current TB control arrangements.

As part of these efforts, three areas for new investment were identified:

1. The establishment of 9 TB control boards at an annual cost of approximately £1.5 million. This was to be covered by PHE’s budget.
2. The establishment of a latent TB screening programme with an annual budget of £10 million, centrally commissioned by NHSE.
3. The expansion of an outreach service, similar to London’s Find & Treat service, to the rest of England. This was estimated to cost £900,000.



## The Inquiry

In 2017, the APPG TB launched a call for evidence as part of its inquiry. The APPG invited written submissions into all aspects of the Strategy and its implementation, with a particular interest in the following:

1. The overall effectiveness of the Strategy;
2. The Strategy's ten evidence-based areas for action and the resources allocated to these; and
3. Accountability mechanisms introduced by the Strategy to monitor and evaluate progress made.

## Written Evidence

Written evidence was received from the following stakeholders;

- Dr Fran Child, Dr Louise Turnbull, Christine Bell & Susanne Dixon, Manchester University NHS Foundation Trust and North West Paediatric Allergy and Infection ODN.
- Dr Wouter Peters, Centre for Global Ethics, University of Birmingham
- Dr Jessica Potter, MRC Doctoral Research Fellow, Queen Mary University of London
- Dr Al Story PhD FFPH MPH RGN, Clinical Lead and Manager, Find & Treat
- Homerton University Hospital TB team
- London Borough of Newham
- London Borough of Redbridge TB Partnership
- Prof Onn Min Kon, British Thoracic Society Joint Tuberculosis Committee
- Public Health England and NHS England (joint submission)
- Royal College of Physicians of Edinburgh
- TB Alert
- University College London TB Network
- Yorkshire and Humber and North East TB Control Board

## Oral Evidence

On 22 May 2018, the APPG TB hosted a roundtable discussion. The event, which took place in lieu of oral evidence sessions, gave the National TB Programme a chance to present their work before opening the floor to questions and short interventions from the APPG and key stakeholders.

## APPG Panel

- The Rt Hon Nick Herbert CBE MP, Co-Chair of the APPG on Global TB
- Virendra Sharma MP, Co-Chair of the APPG on Global TB
- Nic Dakin MP, Vice-Chair of the APPG on Global TB

## List of Witnesses (alphabetical order)

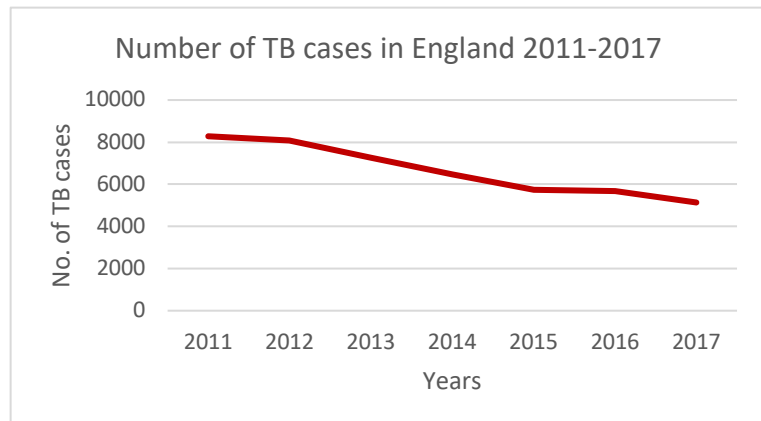
- Stella Abiona, Lead TB Nurse Specialist, Oxleas NHS Foundation Trust
- Lynn Altass, National TB Strategy Programme Manager, NHSE
- Dr Sarah Anderson, Head of National TB Office, PHE
- Dr Susan Collinson, TB Case Worker, Homerton University Hospital

- Prof Paul Cosford, Director of Health Protection and Medical Director, Public Health England
- Dr Martin Dedicoat, Consultant Physician, Heartlands Hospital Birmingham
- Rita Enuechie, TB Nurse, Guy's & St Thomas' NHS Foundation Trust
- Matthew Fagg, Deputy Director, Reducing Premature Mortality, NHS England
- Tony Johnson, Associate Director, Office of London CCGs
- Prof Onn Min Kon, Head of Tuberculosis Service, Imperial College Healthcare Trust; Professor of Respiratory Medicine, Imperial College London; and Chair of the Joint Tuberculosis Committee, British Thoracic Society
- Abbie Malambo, Health Protection Officer, Redbridge Council
- Mike Mandelbaum, Chief Executive, TB Alert
- Amy McConville, TB Action Group
- Prof Timonthy McHugh, Professor of Medical Microbiology and Director of University College London Centre for Clinical Microbiology
- Prof David Moore, Professor of Infectious Disease and Tropical Medicine, London School of Hygiene and Tropical Medicine
- Margaret Ogendengbe, Clinical TB Nurse Manager, Guy's & St Thomas' NHS Foundation Trust
- Dr Al Story, Clinical Lead and Manager for Find & Treat, University College Hospitals NHS Foundation Trust
- Jacqui White, Clinical Team Lead, North Central London TB Service; representing TB Nurses Network
- Dominik Zenner, Head of TB Screening, PHE

Further oral evidence was received from Mike Mandelbaum (CEO of TB Alert), Dr John Watson (consultant in public health medicine) and Prof Timothy McHugh and Dr Marc Lipman (University College London Hospital).

## Overall effectiveness of the Strategy

As stated in the inquiry’s terms of reference, the APPG was keen to evaluate the overall effectiveness of the Strategy in achieving its stated objectives of “a year-on-year decrease in incidence, a reduction in health inequalities and, ultimately, the elimination of TB as a public health problem in England”. As data reported in the Annual TB reports show, there has been a sustained 10% decrease in TB rates since 2011. While the decline seemed to level off in 2016, data for 2017 align with the -10% trend.



In a paper published last year (Thomas et al, 2018), Public Health England demonstrated that “two-thirds of the reduction in TB notifications cannot be explained by changes in migration”, providing strong evidence that new TB control interventions, both in the UK and through pre-entry screening (PES), are starting to have an impact. Since only around 11.4% of the reduction in TB cases can be attributed to PES, the authors conclude that more than half (54.4%) of the reduction in TB cases “was due to reductions within the UK, independent of either changes in migration or the impact of PES”.

Tuberculosis

ORIGINAL ARTICLE

### Reduction in tuberculosis incidence in the UK from 2011 to 2015: a population-based study

H Lucy Thomas,<sup>1</sup> Ross J Harris,<sup>2</sup> Morris C Muznyamba,<sup>1</sup> Jennifer A Davidson,<sup>1</sup> Maeve K Lalor,<sup>1</sup> Colin N J Campbell,<sup>1,3</sup> Sarah R Anderson,<sup>1</sup> Dominik Jenner<sup>1,3</sup>

**Abstract** Following nearly two decades of increasing tuberculosis in the UK, TB incidence decreased by 32% from 2011 to 2015. Explaining this reduction is crucial to informing ongoing TB control efforts.

**Methods** We stratified TB cases notified in the UK and TB cases averted in the UK through pre-entry screening (PES) between 2011 and 2015 by country of birth and time since arrival. We used population estimates and migration data to establish denominators, and calculated incidence rate ratios (IRRs) between 2011 and 2015. We calculated the contribution of changing migrant population sizes, PES and changes in TB rates to the reduction in TB notifications.

**Key messages**

- **What is the key question?** Why has tuberculosis incidence in the UK fallen by nearly one-third between 2011 and 2015?
- **What is the bottom line?** Large decreases in TB rates across almost all population groups explain the majority of the reduction in TB notifications in the UK between 2011 and 2015, with only one-third of the decline due to decreases in the numbers of migrants from high TB burden countries.

Respiratory Diseases Department, National Infection Service, Public Health England, London, UK  
<sup>1</sup>Statistics, Modelling and Economics Department, National Infection Service, Public Health England, London, UK  
<sup>2</sup>Institute for Global Health, University College London, London, UK  
<sup>3</sup>Respiratory Diseases Department, National Infection Service, Public Health England, London, UK

While the majority of the period under study (2011-2015) falls before the launch of the Strategy, PHE emphasise that the Strategy itself is based on many of the interventions that were trialled in that period. Indeed, aspects of the Strategy itself were beginning to be implemented as early as 2013. These findings support the conclusion that the evidence-based interventions laid out in the Strategy are proven to be effective

in driving down TB rates when implemented fully. Indeed, the written and oral evidence presented in subsequent chapters is testament to the quality of the Strategy as a whole.

It should be noted, however, that while a sustained 10% annual decline is testament to the strategy’s effectiveness, there has been no significant acceleration since the 2015 launch of the Strategy and there is still room for improvement. While we recognise that the length of TB treatment means that epidemiological data will inevitably take a year to reflect progress, these data very much reflect the experience reported by TB stakeholders throughout England in written and oral evidence provided to the APPG. Witnesses praised the Strategy as a whole, welcoming a revived sense of strategic direction and the shift away from ‘cough to cure’ models of care in favour of integrated and multisectoral action as well as reformed structures and mandates for organising TB control in England. There was also widespread praise for the support offered by the National TB Office. A number of witnesses also recognised, however, that “the system took a while to bed in” as regional and local

leadership was built and that, as a result, the full impact of the Strategy was only now beginning to be felt.

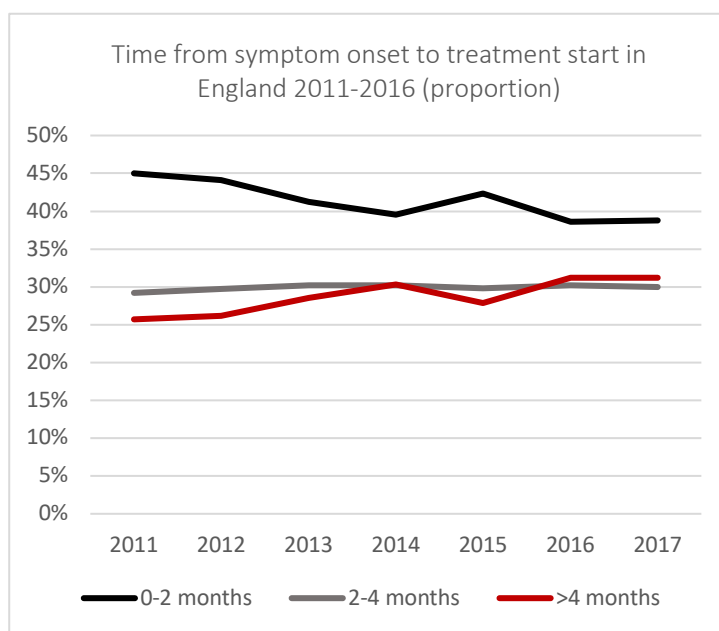
With this in mind, the subsequent chapters consider all ten evidence-based areas for action, evaluating progress made and identifying areas where further efforts will be needed to ensure that the Strategy fulfils its objectives. In the final section, we consider the long-term sustainability of the Strategy and look towards the national TB response after 2020.

## Evidence-based areas for action

The Strategy defined ten evidence-based areas for action to provide a framework for specific services and targets that address TB control needs. This chapter will summarise the evidence received, both written and oral, and make a series of recommendations in relation to each of these areas for action. It should be noted that there is significant overlap between each of the areas for action. During the writing of this report, efforts were made to ensure adequate discussion of key areas for improvement without repetition. The recommendations should therefore be understood as a whole rather than merely isolated to the specific area for action under which they are presented.

### A1. Improve access to services and ensure early diagnosis

Diagnostic delay, or the time between symptom onset and the start of treatment, is a key indicator for a TB programme's effectiveness. This continues to present a challenge in England, where diagnostic delay has worsened slightly since the launch of the strategy. In 2017, nearly one third (31.2%) of patients experienced a diagnostic delay of more than 4 months, 5.5% more than in 2011. This is not only a concern because the disease is likely to progress to a more advanced stage during this time, but also because patients may pass on the infection to other close contacts. PHE reports that analysis done to understand diagnostic delay has shown that delays tend to be very short once patients are referred to TB services but that many individuals either do not seek healthcare or have numerous interactions with healthcare services before TB testing is completed.



In this context, the importance of raising awareness to encourage care-seeking behaviour, TB testing and addressing TB stigma was noted by a number of witnesses. PHE and NHSE have supported the national TB charity, TB Alert, in developing and updating awareness-raising literature and online resources, including its website, *The Truth About TB*, for both affected communities and healthcare professionals. These resources, as well as e-learning modules developed by the Royal College of General Practitioners, were noted as particularly useful by a number of witnesses. Other

innovative means of improving the accessibility of TB services include the Borough of Newham's extended opening hours of TB clinics and Redbridge's 'Health and Wellbeing

Buddies’ commissioned through a local third-sector organisation. In all these cases, however, witnesses noted that the availability and sustainability of these interventions was highly contingent on the availability of flexible funding through local authorities and health services. Respondents also noted that such interventions would become more relevant as overall TB incidence reduced, on the grounds that this led people to become more complacent about the threat posed by TB. This would likely be compounded by the fact that a growing proportion of the overall TB burden is concentrated among under-served populations who already struggle to access TB services.

The APPG therefore makes the following recommendations:

- iv. Strengthen awareness raising activities among healthcare workers, including in areas of low TB incidence.
- v. Convene stakeholders, at the appropriate level, to develop fully-funded plans for reducing diagnostic delay, including through improved accessibility of care services, outreach activities and awareness raising, as well as through appropriate commissioning arrangements and the involvement of third sector organisations.

## **A2. Provide universal access to high-quality diagnostics**

PHE conducted a national diagnostic audit and reports using the findings to strengthen diagnostic capability at the regional level. While these findings have not been published, respondents from BTS, TB Alert, Yorkshire, Humber and North East TB Control Board and University College London all noted that the availability of key diagnostic tests remained “patchy” nationally. Advances in diagnostic tests, according to respondents, had a limited impact on TB services locally and both Interferon Gamma Release Assay (IGRA) and Polymerase Chain Reaction (PCR) technologies remained unavailable in some high-incidence areas. While PHE note that a forthcoming reform of accreditation standards for laboratories may have a positive impact on the availability of key diagnostic tools, their accessibility for TB services remains contingent on CCGs commissioning these tests as a core part of their TB provision. In this context, Prof Onn Min Kon, Chair of the British Thoracic Society’s Joint Tuberculosis Committee, recommended that PCR tests be considered a key performance indicator for commissioning standards as a means of ensuring CCGs appropriately commission high-quality diagnostic services for TB.

At the national level, the roll-out of whole genome sequencing (WGS) as a routine diagnostic was described as “successful and an international first”, putting PHE at the forefront of the technology’s development. During oral evidence, witnesses agreed that significant lessons had been learned about the use of the technology since the Strategy’s launch and that it had made a significant scientific contribution. BTS noted that additional work was needed in terms of how data is presented to clinicians, with participants of the roundtable recounting the challenges they faced in effectively interpreting the wealth of data generated through WGS. Prof Tim McHugh pointed out that a retrospective analysis of WGS’ predecessor, MIRU-typing, had found limited impact on clinical services generally and recommended that an evaluation of the impact of WGS on both clinical services and the TB programme be

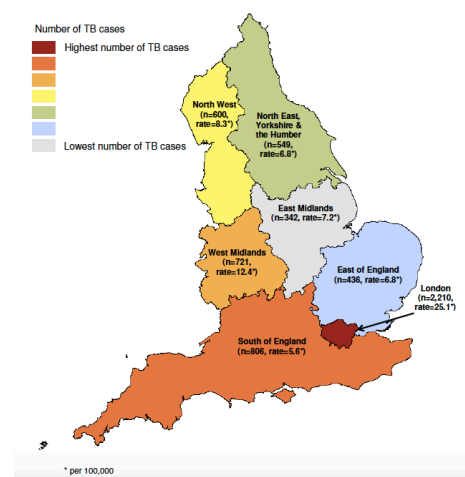
conducted to ensure that levels of investment were commensurate with the needs of public health delivery.

The APPG therefore makes the following recommendations:

- i. Ensure appropriate commissioning of recommended diagnostic tests for TB and LTBI nationally.
- ii. Consider the inclusion of PCR and IGRAs within key performance indicators of service specifications to ensure appropriate commissioning.
- iii. Conduct a comprehensive evaluation of WGS technology to facilitate further learning.

### A3. Improve treatment and care services

The creation of new structures, including regional TB control boards, was widely noted to have had a positive impact on TB control efforts in England, particularly by formalising mandates and relationships among implementing partners. As a result of this work, clinical networks were strengthened, with respondents noting the benefit of local cohort review mechanisms and new pilot schemes such as the Manchester paediatric pathway. In written and oral evidence, respondents underlined the importance of multisectoral teams to address comprehensively the needs of people with TB. In areas where the collaborative aspects of the Strategy had been implemented fully, a positive impact on treatment and care services, and by extension TB epidemiology, was noted. This includes both Newham and Redbridge's TB Partnership, the pan-London risk-share agreement among CCGs to cover the cost of accommodation for vulnerable people with no recourse to public funds, and the definition of local service indicators by CCGs in the North West.



The development and funding of multisectoral care plans, however, remain contingent on joint-leadership from local public health and social care authorities as well as CCGs. In written evidence, Prof Onn Min Kon noted that the variability in arrangements nationally was largely due to commissioners not fully engaging in TB control efforts, a view that was also shared by TB Alert, the Yorkshire and Humber and North East TB Control Board, and a number of other witnesses during oral evidence. While witnesses agreed that leadership ultimately needed to come from the Directors of Public Health, Health and Wellbeing Boards, CCGs and Acute Care Trusts themselves, it was recognised that particularly in areas of lower incidence this engagement was difficult to secure by TB Control Boards alone. At the launch of the Strategy, PHE and NHSE emphasised their intention to use 'soft levers' to encourage leadership, and Prof Dr Paul Cosford noted the National TB Office's ongoing efforts to create an enabling environment. Witnesses did, however, note that regional engagement on the part of NHS

England had been more limited and called for further leadership and accountability through these structures.

This will become increasingly relevant as TB incidence rates continue to decline. In written evidence, the Yorkshire and Humber and North East TB Control Board noted the challenges faced in managing pockets of TB in otherwise low-incidence areas that were ineligible for the same level of support as high-incidence areas. TB Alert recommended the establishment of a national working group to develop best-practice recommendations and plans for TB control efforts in low-incidence areas.

The APPG recognises the significant advances made in reorganising TB services nationally and the leadership demonstrated by Strategy partners, the National TB Office, regional TB control boards and local TB teams. To improve service provision further and ensure consistency in the quality of TB services nationally, the APPG makes the following recommendations:

- iii. Establish a national working group on TB in low-incidence areas to determine how services can be run and funded most effectively in these areas.
- iv. Explore additional measures to drive local action and leadership, including through more coherent engagement of regional NHSE offices and strengthened accountability measures for Strategy partners.

#### **A4. Ensure comprehensive contact tracing**

Contact tracing is a resource-intensive but essential element of TB control efforts and is currently conducted by local TB services with the support of PHE health protection teams. The development of new NICE guidelines has provided additional clarity. During oral evidence, Dr Anderson explained that the reduction in TB incidence meant that the total workload of doctors and nurses should have been sufficiently reduced to allow expanded contact tracing. However, BTS, Homerton University Hospital TB Team, the London Borough of Newham, TB Alert and a number of TB nurses in oral evidence noted insufficient resources to conduct expanded contact tracing combined with increased workloads as the result of the LTBI screening programme and outbreak response. Dr Jessica Potter, Dr Susan Collinson and Mike Mandelbaum all emphasised the special challenges faced when conducting contact tracing in hard-to-reach populations (see area for action 7) and noted that the 'community outreach workers' recommended by the Strategy were not widely available.

Dr Anderson noted that regional cohort reviews showed some improvement in the number and quality of contact tracing efforts. Despite being included as a key monitoring indicator at the Strategy's launch in 2015, this data is currently not reported on nationally. The collection and reporting of this data would better enable local services to assess the workload of their existing TB teams and evaluate the extent to which both contact tracing and staffing levels are appropriate to local needs.

During the roundtable, discussion also turned to the potential role of WGS in better targeting contact tracing efforts. The need to evaluate the impact of WGS on clinical services has already been underlined in area-for-action 2, but in relation to contact tracing in particular Dr



Martin Dedicoat, Prof Tim McHugh, Prof Onn Min Kon and a number of TB nurses reported that local teams found it difficult to interpret WGS results. To make the most of this technology, discussants agreed that further capacity building should be made a priority under both area-for-action 2 and 4.

Recognising the progress made and noting the need for further data to evaluate the implementation of this area for action fully, the APPG makes the following recommendations:

- iv. Improve monitoring and reporting of contact tracing data at local, regional and national level.
- v. Evaluate current workloads and ensure appropriate staffing levels for comprehensive contact tracing.
- vi. Undertake necessary capacity building to ensure WGS data is effectively used in contact tracing efforts.

## **A5. Improve BCG Vaccination Uptake**

Progress in this area for action was severely hampered by a stock-out of BCG vaccines on the part of the manufacturer in 2015/16. PHE was able to secure an alternative supply of the InterVax BCG vaccine to cover 2017 and 2018 and has made this area-for-action a priority for 2018. In the absence of a UK licence for InterVax, it will be imperative to take pre-emptive steps to secure BCG vaccines from 2019 onwards irrespective of ongoing challenges faced by the manufacturer of the licenced BCG vaccine.

In addition to the stock-out, the limited availability of data has hampered the evaluation of progress in this area-for-action. The inclusion of BCG data in the COVER database will facilitate better assessment of BCG vaccination uptake and facilitate evidence-based interventions to improve it. Prof Onn Min Kon drew special attention to the need to improve catch-up provision for those children who missed out on vaccination as a result of stock-out or uptake issues. TB Alert also noted ongoing discussions with the Royal College of Midwives to this effect.

Recognising the above, the APPG therefore makes the following recommendations:

- i. Secure BCG vaccination supply from 2019 onwards.
- ii. Utilise COVER data to guide interventions to improve BCG uptake and catch-up programmes.
- iii. Facilitate engagement with Royal College of Midwives and other bodies to ensure appropriate training and awareness among healthcare providers.

## **A6. Reduce drug-resistant TB**

Respondents noted that clinical services for MDR-TB were generally strong and that clinical networks, instituted by or strengthened as a result of the strategy, were working effectively. The BTS' clinical advice service for MDR-TB was praised for the support it offered to clinicians

treating people with MDR-TB and now plays an integral part of the specialist commissioning arrangements for novel MDR-TB drugs. Prof Onn Min Kon emphasised that current funding will only secure the service for two years and that sustainable funding will be absolutely essential to maintain the service beyond that. In light of recent updates to WHO treatment recommendations, including the more widespread use of novel TB drugs such as bedaquiline, the long-term sustainability of the service and specialist commissioning for novel TB drugs must be secured as a matter of urgency.

In addition to the maintenance of the BTS advice service, a number of informants highlighted the potential role of Video-Observed Therapy (VOT) as opposed to directly observed treatment (DOT), which is more labour-intensive for staff and burdensome to patients who might need to travel significant distances to receive treatment. Results from a recent pilot study are very promising and are likely to be of increasing relevance as incidence rates drop and a greater proportion of people with TB have complex care needs. These discussions should be integrated into the work of national working groups to explore possible models of commissioning VOT where the model supports improved person-centred care and treatment completion, and/or where staff resources are not sufficient for DOT service provision.

Given the length of treatment for drug-resistant strains of TB, data are not yet available for patients enrolled on MDR-TB treatment under the new strategy. Noting the need to monitor this data closely to ensure that interventions are having the desired effect, the APPG recognises progress made in improving MDR-TB services nationally and makes the following recommendations:

- i. Secure sustainable funding for BTS MDR-TB clinical advice service.
- ii. Explore the potential role of VOT in TB and DR-TB treatment provision, including through commissioning models.
- iii. Continue to monitor MDR-TB treatment outcomes closely.

## **A7. Tackle TB in under-served populations**

The Strategy rightly recognised the special measures that would need to be taken to address TB in under-served populations, who are not only at a higher risk of developing TB but also of contracting or developing drug-resistant strains of the disease. The newly-launched toolkit for tackling TB in under-served populations emphasises the importance of multidisciplinary care teams by building on existing NICE guidelines. This is an area that many respondents recognised as needing additional support. The Homerton University Hospital TB team's submission, for example, highlighted that many of their patients' needs transcended the capacity of clinical teams and required active intervention from social care, housing, migration and other services in order to support treatment completion. As noted previously, great successes have been reported where Strategy partners have facilitated multidisciplinary and collaborative responses. The pan-London CCG risk-share arrangement, which covers the costs of housing for those without recourse to public funds, offers an excellent example of this kind of collaborative working. TB Alert's patient support fund offers another valuable proposal for addressing under-served populations' needs. As noted in area-for-action 3, Strategy partners should work with regional and local counterparts to develop

and fund similarly innovative solutions, including through the flexible allocation of health and social care budgets and the specialised commissioning of third sector organisations. In the vast majority of cases, such interventions would be of both low cost and high impact.

The specific challenges faced by migrant communities were highlighted by both Dr Potter and Dr Colinson, who noted that while TB diagnosis and care was provided free of charge, awareness of this policy was limited. Furthermore, widespread concern over NHS charging and immigration enforcement meant that care seeking and contact tracing were rendered far more difficult, despite recent reform of data-sharing arrangements between NHS Digital and the Home Office. Such fears have a significant detrimental effect not only on the individual patient concerned but also case-finding within the community and hamper efforts to control the epidemic. During the roundtable discussion, PHE noted ongoing collaboration with the Home Office to update the Migrant Health Guide. While such efforts are welcome, the translation of this guidance into user-friendly resources and active awareness-raising campaigns – including among NHS trusts, staff, and affected communities – must be actively pursued, including through collaboration with and support for third sector organisations. The TB programme should continue to monitor diagnostic delay closely and gather data for the factors leading to late care seeking so that policy changes and programmatic interventions can be appropriately designed and targeted.

The APPG noted with concern that London’s Find & Treat service has yet to be rolled out nationally despite its being one of three central areas of investment announced at the launch of the Strategy. During the oral evidence session, PHE noted that it had made significant efforts to secure funding but had thus far been unsuccessful as the service crosses the institutional and geographical boundaries that traditionally delineate funding responsibilities. The London service offers a fully-integrated model including social workers, DOT and VOT. This model increases capacity for responding to outbreaks and facilitates the integration of screening for HIV and Hepatitis, as well as for LTBI. The model is cost-effective, and urgent steps should be taken to fund both the initial set-up and the running costs of a national Find & Treat service.

With rates of TB among under-served populations out of step with the overall downward trajectory of TB in the UK, including with some increases in recent years, this area for action requires urgent prioritisation and investment. Recognising that these interventions are both time and resource intensive, the APPG makes the following recommendations:

- iv. Ensure multidisciplinary care teams are strengthened, through active involvement from local authorities.
- v. Strengthen awareness-raising and active case finding activities among under-served and hard to reach populations, including, where appropriate, through the specialised commissioning of third-sector organisations.
- vi. Fully fund the roll-out of a national Find & Treat service.

## A8. Systematically implement new entrant latent TB (LTBI) screening

The new entrant LTBI screening programme was the largest area of investment announced as part of the new Collaborative TB Strategy for England, with up to £10 million having been made available annually since 2015. In their written evidence (January 2018), NHSE reported having disbursed £13.29 million to CCGs for LTBI screening thus far, with LTBI testing and treatment now being implemented in 59 eligible CCGs and over 27,300 tests reported since the programme commenced in 2015. Despite this investment, both testing and treatment uptake rates remain a challenge. According to the most recent Annual Report, only 1,124 people are reported to have started LTBI treatment between July 2014 and June 2017. Of the total number, only 806 people are reported to have completed treatment.

The commissioning of TB Alert to support eligible CCGs in improving testing and treatment uptake among eligible populations is therefore welcomed. However, the lack of quality LTBI data being reported by CCGs who are receiving funding remains a major concern, and the full implementation of the newly launched LTBI database should be made an absolute priority. The availability of these data will not only be imperative to monitoring and evaluating the implementation of the screening programme and the effectiveness of TB Alert's additional interventions, but will also be essential for an accurate evaluation of the cost-effectiveness of the Strategy's most significant investment. On the basis of current data alone, it is difficult to justify the current programme's limited eligibility criteria or, indeed, the apparent lack of funding for other key TB services.

While the APPG welcomes the investments made in tackling LTBI in England, the APPG notes its concern over reported outcomes thus far and makes the following recommendations:

- iv. Accelerate efforts to significantly improve testing and treatment uptake within the LTBI Screening Programme.
- v. Ensure quality reporting from CCGs who receive funding for the LTBI screening programme.
- vi. Evaluate the cost-efficiency of the LTBI screening programme and, if necessary, consider steps to improve it.

## A9. Strengthen surveillance and monitoring

In both written and oral evidence, witnesses noted significant improvements in both the quality and accessibility of data since the launch of the Strategy. Annual TB reports, regular strategy implementation updates, PHE's Fingertips platform, and breakdowns of data by local authority and parliamentary constituencies have supported academics as well as local and regional TB control teams in analysing local epidemics and developing evidence-based intervention models. As noted under the previous areas-for-action, some specific reporting systems and data-sets still fall short of the high standard otherwise set across the National TB Programme, and additional work is needed to strengthen BCG, contact tracing and LTBI programme data in particular. The proactive use of this data in driving and shaping local authority and CCG action in local TB responses should be encouraged at both the national and regional level.

The APPG praises the quality and availability of TB data in England and makes the following recommendations:

- iii. Strengthen data reporting on BCG, contact tracing and LTBI programmes in particular.
- iv. Ensure data are being used proactively to hold Strategy partners to account for delivering on their institutional responsibilities.

#### **A10. Ensure an appropriate workforce to deliver TB control**

Since 2015, PHE and NHSE have conducted reviews of both the nursing and the wider TB workforce and are planning a review of the medical workforce in 2018. Findings from the nursing review were used to develop a new competency framework, outline job descriptions, and strengthen the national TB nursing network. PHE and NHSE also note plans to use findings from the wider TB workforce review to “build a multidisciplinary approach to improve the care of people with TB”. It is notable that both TB Alert and the British Thoracic Society highlighted uncertainty over national staffing levels. Making findings from these reviews more accessible to stakeholders would not only enable them more accurately to evaluate the degree to which this area for action is being delivered on, but would also facilitate the greater accountability necessary to drive local leadership.

During the oral evidence session, Public Health England noted that reductions in total incidence rates meant that current workforce levels were sufficient for delivering services. This assessment was questioned, however, by witnesses including BTS, Homerton University Hospital TB Team, the London Borough of Newham, TB Alert, and a number of TB nurses, who observed that there were insufficient resources to deliver resource-intensive services such as expanded contact tracing and community outreach. In its written evidence, TB Alert noted that there had been “little evidence” of the use of ‘community outreach workers’ who would be able to address these needs. Respondents also noted that newer programmes including LTBI screening and urgent outbreak response had added to their workload and were rarely reflected in staffing allocations.

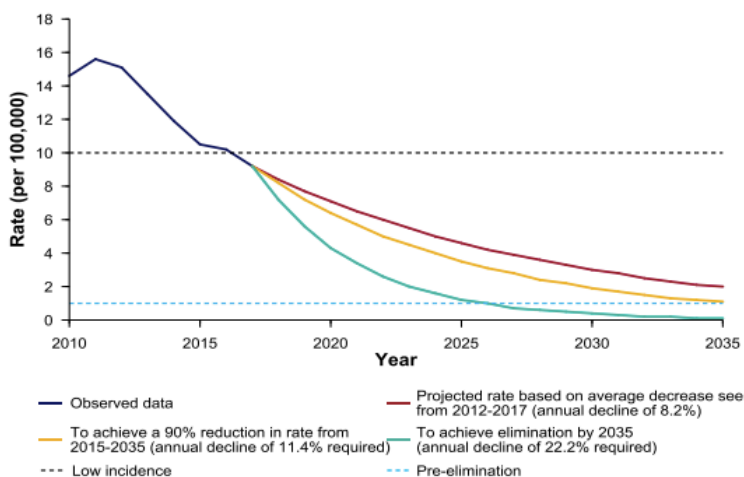
In this context, there was agreement among witnesses that decreasing incidence rates should not lead to any reduction in workforce. NHSE confirmed that the LTBI programme funding could be used to support additional staff costs but recognised that this had rarely been done by local trusts. In this context, as well as in the context of reported challenges in securing funding from CCGs and local authorities for multidisciplinary care teams, the production and release of more comprehensive data on TB workforce, workload and impact would likely be beneficial in developing local investment cases.

Taking note of both written and oral evidence, the APPG therefore makes the following recommendations:

- i. Make findings from workforce reviews publicly available.
- ii. Improve data reporting to ensure that current workforce levels are appropriate and shape investment cases in areas where staffing levels remain insufficient.

## Long-term sustainability of TB control in England

The evidence provided to this inquiry clearly demonstrates the positive impact of the Strategy on the TB response in England. While there are certainly areas for improvement, this only creates scope for the Strategy to have a greater impact. Indeed, the APPG has been pleased to see the implementing partners' consistent efforts to address areas of concern, including many raised throughout this report. The recommendations outlined above should be taken in this same light and be seen as a means of ensuring that the Strategy is implemented to its full effect.



Observed and projected rate of TB notifications, England, 2010-2035 (PHE 2018, Annual TB Report, p12)

Looking beyond 2020, however, it is clear that the Strategy will not achieve the overall objective of 'ending TB as a public health concern in England' by 2020. Projections developed as part of the most recent Public Health England annual TB report clearly illustrate the additional efforts required to attain these objectives, with a continuation of current trends remaining

insufficient to reach End TB Strategy targets. Indeed, initial analysis suggests that the relative proportion of complex TB cases is set to grow as rates continue to decline, which will require more intensive management and necessitate the kind of regional and national collaboration and sharing of expertise and resources that the Strategy has begun to establish and facilitate.

History has also shown the danger of becoming complacent about TB. The now infamous 'New York curve' (pictured) demonstrates the impact of the strategic and fiscal deprioritisation of TB programmes. In 1968, the New York City TB programme launched a new strategy including a comprehensive USD \$40 million funding programme to cover patient-centred care models. The impact on TB incidence was clear,

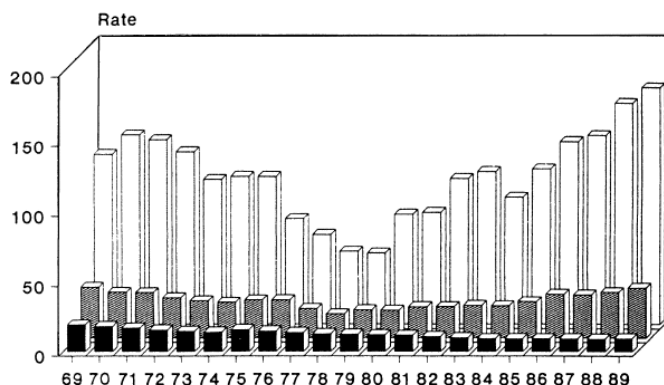


Fig. 1. Tuberculosis case rates for the United States, New York City, and central Harlem from 1969 to 1989 per 100,000 population. Closed bars = United States; hatched bars = New York City; shaded bars = Harlem.

with significant decreases in TB rates between 1969 and 1980. In the late 1970s, however, New York City was in the midst of a financial crisis and the TB programme was dramatically

scaled back. By 1978, the city government was spending half of its previous annual investment, and inpatient beds had been drastically reduced with no additional investment in outpatient care or public health interventions. The dramatic increase in TB cases, combined with the impact of an escalating HIV crisis, remains striking with incidence rates rising to pre-1969 levels within a decade.

In this context, it is vital that the Collaborative TB Strategy for England 2015-2020 is not seen as an individual strategy but instead as an important starting point for a concerted national effort to end TB as a public health issue in England. Indeed, the UN High-Level Meeting on TB provides an impetus for the development of a post-2020 strategy to protect the progress made since 2011, to demonstrate the effectiveness of evidence-based and collaborative public health interventions in England, and to participate in global efforts to reach the goals spelled out in the UN High-Level Meeting's political declaration.

To ensure this work continues, it is imperative that TB remains a priority for both Public Health England and NHS England. The APPG therefore makes the following recommendations:

- v. Begin work to develop a post-2020 TB Strategy for England.
- vi. Work with partners to ensure that said Strategy is fully funded.
- vii. Continue the close monitoring of TB rates in England and adjust intervention models accordingly.
- viii. Maintain TB as a strategic priority for Strategy partners.